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Priority to End of Life Treatments? Views of the Public in the Netherlands

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Abstract

Objectives Recent debates in the Netherlands on health care priority setting have focused on the relative value of gains generated by life-extending medicines for people with a terminal illness, mostly new cancer drugs. These treatments are generally expensive, provide relatively small health gains, and therefore usually do not meet common cost per QALY thresholds. Nevertheless, these drugs may be provided under the assumption that there is public support for making a special case for treatments for people with a terminal illness. This study investigated the views of the public in the Netherlands on a range of equity and efficiency considerations relevant to priority setting and examines whether there is public support for making such a special case.

Methods Using Q methodology, three viewpoints on important principles for priority setting were identified. Data were collected through ranking exercises conducted by 46 members of the general public in the Netherlands, including 11 respondents with personal experience with cancer.

Results Viewpoint 1 emphasized that people have equal rights to healthcare and opposed priority setting on any ground. Viewpoint 2 emphasized that the care for terminal patients should at all times respect the patients' quality of life, which sometimes means refraining from invasive treatments. Viewpoint 3 had a strong focus on effective and efficient care and had no moral objection against priority setting under certain circumstances.

Conclusions Overall, we found little public support for the assumption that health gains in terminally ill patients are more valuable than those in other patients. This implies that making a special case for people who have only a short period of lifetime left, does not correspond with societal preferences in the Netherlands.

Introduction

Health care systems face an enormous challenge due to rapidly increasing demand for health care, beyond a level supported by available resources. Priority setting is essential to keep the health care system viable, which requires decision makers to make difficult choices regarding the treatments and technologies to fund within the health care system. Increasingly economic evaluations are used to inform such decisions, and in many countries, formal Health Technology Assessment (HTA) agencies have been established to inform health care decision making at the national level [1-3].

Economic evaluations inform decision makers about the costs and benefits of an intervention and help them to identify those interventions that represent the best value for money, generally expressed in terms of costs per gained quality adjusted life year (QALY). Such studies traditionally treat all costs and all effects equally [4, 5]. That is, health gains receive equal value regardless of how they are generated or who benefits, and equal costs per QALY ratios are considered to be equally 'good'. However, an increasing body of literature suggests that valuing all health gains equally may not reflect societal preferences. Different studies have shown that people care, for example, about the nature and cause of illness and characteristics of the beneficiaries of health gains [6-16]. The social value of health gains apparently varies and depends on contextual information.

Many recent debates in this area have focused on the relative value of health gains generated by life-extending medicines for people with a terminal illness, mostly new cancer

drugs [1, 17-20]. These newly developed cancer drugs are generally expensive and often provide relatively small health gains, resulting in poor cost-effectiveness ratios. Because such small health gains may still be considered to be very significant to terminally ill patients and society, it may be appropriate to evaluate the cost-effectiveness of such interventions with greater flexibility. In England, for example, the National Institute for Health and Care Excellence (NICE) has made the decision to allow a higher cost-effectiveness threshold for treatments that provide short life extensions to terminally ill patients [21]. However, this has raised the question whether the implied higher social value of a QALY for end of life treatments is indeed in line with societal preferences.

The empirical evidence for the relative value of end of life treatments is limited [1] and provides mixed guidance. None of these studies are from the Netherlands. Some studies find support for a higher value for treating people with a terminal illness [22-25], but others do not [26-28]. A recent study in the UK identified three viewpoints in a sample of people with professional expertise or personal experience in end of life issues in the context of priority setting and the value of life extending treatments. Only one of the three viewpoints was found to support the decision by NICE to raise the cost-effectiveness threshold for life-extending end-of-life treatments – contingent on there being significant benefit from treatments, value for money and good quality of life [1].

In the Netherlands, cost-effectiveness is an explicit appraisal criterion in drug reimbursement decisions, and guidelines for pharmacoeconomic evaluations recommend that such evaluations take a societal perspective [29]. Still, there is lack of transparency about how the outcomes of an evaluation study are weighted against other aspects in subsequent reimbursement recommendations and decisions [14, 30]. First, although several explicit appraisal criteria are applied in reimbursement decisions, such as cost-effectiveness,

added therapeutic value, medical need, severity and feasibility, 'other' (less explicit) criteria can also be considered. Second, there is no explicit guidance about the relative value of each of these criteria for reimbursement recommendations. Third, a bandwidth of acceptable cost-effectiveness ratios was recommended, from €10,000 for low severity to €80,000 for high severity [31, 32]. However, although 'proportional shortfall' [14, 33] is nowadays systematically used as criterion for severity and accommodates taking into account the severity of shortfall in both quality and length of life, low and high severity of illness have not been formally defined, and there is no formal maximum on cost-effectiveness ratios either [30, 34].

Recent policy recommendations imply that, based on severity of illness arguments, end of life treatments have a relatively high social value. Busschbach and Delwel, for instance, argued that "… if a patient for example has only few life years left (the life-threatening situation), we are prepared to pay more" [34]. Although this suggests that there is societal support for the provision of costly end of life treatments in the Netherlands, there actually is little empirical evidence for this.

Therefore, this study aimed to investigate the heterogeneity in views of the public on a range of equity and efficiency considerations that were shown to be relevant for health care decision-making, and to examine whether any of these views express support for making a special case for reimbursing costly end of life treatments.

Methods

Q methodology

We used Q methodology [35-37] to explore the diversity of views on health care priority setting in the Netherlands, and our work builds on methods and findings from three recent

studies with similar aims [1, 12, 15]. This study differs from two of these studies [12, 15] by its particular interest in the relative value of costly end of life treatments, and from the third study [1] by exploring end-of-life considerations within a broader context of societal preferences and by including a sample of people with personal experience with cancer. It differs from all three studies by focusing on the decision-making context in the Netherlands.

Q techniques are systematic methods designed to identify and describe the *nature* of subjective views. Respondent sampling has much in common with qualitative methods in the sense that a Q methodology study uses a purposive sample of respondents. These respondents are asked to rank a comprehensive set of statements about some topic, and to explain their ranking.. The ranking is known as a "Q sort" and Q sort data are subjected to by-person factor analysis [35, 38] in order to identify patterns in the ranking of statements. These patterns are then described and interpreted with each distinct ranking representing a different shared viewpoint on the topic of study in the population that was sampled.

Development of the research instrument

We followed several steps in order to arrive at a comprehensive set of statements that are relevant and representative for the decision-making context in the Netherlands regarding health care priority setting in general and in the end of life context in particular. Figure 1 presents a flow diagram of the process.

First, we gathered materials from three previous, related Q methodology studies: the Social Value of a QALY (SVQ) project from the UK [15], the European Value of a Quality Adjusted Life Year (EuroVaQ; http://research.ncl.ac.uk/eurovaq/) project which was conducted in 10 countries and an MRC Methodology Panel funded study on societal values and life extension for people with terminal illnesses (MRC EoL;

http://www.gcu.ac.uk/endoflife/), also from the UK [1]. The SVQ and EuroVaQ projects focussed on principles for health care resource allocation in general and not specifically on end of life issues. The MRC EoL project was more similar to this study and aimed to examine values in relation to resource allocation, with a particular focus on the provision of end of life treatments. There were 46 statements developed for SVQ, 34 for EuroVaQ and 49 for MRC EoL.

Secondly, two researchers [SW, JE] used the conceptual framework dividing statements into different characteristics and dimension developed in the EuroVaQ project [12] to evaluate the pooled set of statements. This conceptual framework contained 23 characteristics potentially relevant for prioritisation of health care extracted from literature, in five domains: characteristics of the patient, characteristics of the illness, characteristics of the treatment, health effects of treatment and non-health effects of treatment. In an iterative process, the two researchers placed all 129 statements in the existing conceptual framework. During this process, one domain[1] was relabelled and a sixth domain added to the conceptual framework[2]. In addition, they combined[3] and added[4] some characteristics, and moved[5] several characteristics between domains. Finally, they placed one statement under a different characteristic[6] and disregarded several statements[7]. The updated conceptual framework contained 126 statements categorized into six domains and 25 underlying characteristics.

[1] 'Non-health effects of treatment' was relabelled into a more general label 'broader effects of treatment'.

[2] The sixth domain was labelled 'moral principles'.

[3] The characteristics 'socio-economic status' and 'payment/contribution' were combined into 'income/contribution'.

[4] The following characteristics were added: 'availability' (characteristics of the treatment), 'side-effects/invasiveness' (characteristics of the treatment), 'dignified end-of-life' (broader effects of treatment), 'patient choice' (moral principles) and 'values' (moral principles).

[5] The following characteristics were placed under a different domain: the characteristic 'having dependents/family effect' was placed under the domain 'broader effects of treatment and the characteristics 'income/contribution' and 'equality' were placed under the domain 'moral principles'.

[6] The statement placed under the characteristic 'waiting lists/waiting time' was moved to the characteristic 'equality' and therefore the now empty characteristic 'waiting lists/waiting time was removed from the conceptual framework.

[7] EuroVaQ statement #12 (and therefore the corresponding characteristic 'health effects should be leading') and SVQ statements #35 and #37 were disregarded because they were deemed irrelevant for the purpose of the current study.

Thirdly, we investigated whether there were any omissions in the aspects covered by the updated conceptual framework. We updated the literature reviews underlying the theoretical framework from the EuroVaQ study [14, 39] by replicating the search strategy for recent years not covered in the reviews. In addition, we gathered material from Dutch newspaper articles, online discussion forums and current affairs programmes that discussed the increasing pressure on the health care budget, costly end of life treatments and priority setting in health care. Careful study of these materials revealed that no additional domains or characteristics of relevance for the purpose of this study.

Fourthly, the researchers reviewed the update conceptual framework and agreed to disregard five of the 25 characteristics, including the 10 corresponding statements. These five characteristics were considered either too specific or less relevant for the purpose of this study, or were observed to be less relevant in the original Q studies. The table included in the Annex lists the final 20 characteristics (second column), categorized into six domains (first column).

Fifthly, the remaining long-list of 116 potentially relevant statements was critically reviewed with the aim to develop a comprehensive and manageable short-list of statements for pilot-testing. The statements in each characteristic were grouped by the issue they addressed, and from the statements addressing the same issue a single statement was selected, or statements were combined. For example, EuroVaQ statement #4 stating that 'Patient characteristics like age, gender or income should play no role in prioritising between people' and SVQ statement #15 stating that 'Everybody, no matter what you are, whether you are young or old, should get the same access to and choice of treatment' were combined and edited into one general statement about equality : 'Patient characteristics other than their health should play no role in prioritising care' (#18). In this way, the long-list was reduced to a draft set of 48 statements.

Finally, because the statements originated from three different studies, with different backgrounds and aims, the two researchers reviewed the wording of all statements, and then separately translated them into Dutch and reached consensus about any differences.

The categorization, selection, editing and translation process was fully documented and critically reviewed by a third researcher [WB]. The translated set and other interview materials (i.e., instructions to participants and follow-up questions) were critically reviewed by two health economists and three lay persons, which led to minor changes in wording.

A sorting grid was designed to guide the ranking procedure, consisting of 9 columns, ranging from 'disagree most' on the left to 'agree most' on the right (see Figure 2).

Selection of respondents

In accordance with a previous Q study in this area [12], we anticipated that views on the relative value of health gains may be related to socio-demographic characteristics of respondents, like their age, level of education, having children and religious beliefs. In addition, because most of the scientific and popular discussion around end of life treatments concerns new and expensive cancer drugs, we were also interested in the views of people who have, or previously had, cancer.

Most participants were recruited by a professional recruitment agency. A total of 31 respondents, were sampled from the public in the Netherlands, according to age (18+), gender, education level and having children. Among these 31 was a group of 10 respondents who identified themselves as cancer patient or survivor. Sampling on the basis of religious beliefs was not possible. All respondents voluntarily signed up to participate in this study and received an incentive of €25 for participation. These respondents were interviewed in six group sessions that were held in the research studio of the recruitment agency and were

moderated by two researchers [SW, JE]. Separate sessions (i.e., the third and fourth) were organized with people with personal experience with cancer (i.e., they identified themselves as cancer patient or survivor to the recruitment agency).

Because information about religious beliefs was not included in the database of the recruitment agency and some relevant subgroups (e.g., lowest education level, elderly above 70 years) failed to sign up for the study, 15 additional respondents were recruited by the research team, through their professional and social networks. For example, a number of elderly respondents were recruited through the database of a researcher that recently conducted a study in that target age group [40]. These respondents received no incentive for participation and were interviewed in their homes.

In total, we collected 46 Q-sorts: 31 in six focus group sessions and 15 in individual interviews.

Data collection

In the first part of the focus group sessions, respondents sat together at a large table and were briefly introduced to the topic and purpose of the study, and shown a two-minute video about the Dutch health care budget and its limits[8]. In the second part, respondents sat individually at smaller tables and were asked to perform the ranking of the statements. They were each provided with a set of statements printed on cards, a sorting grid (see Figure 2), step-by-step instructions for the study, and a response sheet. Respondents read the 48 statements and divided them into three piles: agree, neutral and disagree. Then, they read the statements in the agree pile once again and ranked them on the sorting grid according to

[8] This video - titled "Betaalbaarheid van de Zorg: welke keuzes moeten volgens u worden gemaakt?" - was released on YouTube (http://www.youtube.com/watch?v=k9IwvMhk3BM) in June 2012 by the Dutch Ministry of Health, Welfare and Sports as a part of a national campaign to increase awareness about the Dutch health care budgets and its limits; http://www.rijksoverheid.nl/onderwerpen/betaalbaarheid-van-de-zorg/de-zorg-hoeveel-extra-is-het-ons-waard.

agreement, working from the right side of the grid towards the middle (see Figure 2). Next, they repeated this step for the statements in the disagree pile, placing them on the left side of the sorting grid according to disagreement, working from the left side of the grid towards the middle. Lastly, they added the statements from their neutral pile to the grid, and checked the ranking of the statements and made adjustments until they were satisfied with the ranking as a whole. After completing the ranking exercise, they were asked to give a written explanation of the statements they most agreed and most disagreed with, to write a short statement reflecting their general view about priority setting in health care, and to complete a short questionnaire covering the sampling characteristics and a few additional questions. Finally, in the third part, respondents came back to the large table to round up the session with a group discussion on respondents' view of priority setting in health care and end of life as a special case [JE moderated the discussion; SW took notes]. We also discussed the comprehensiveness and intelligibility of the interview materials, which revealed no omissions or any other problems. This final third part of the focus group sessions was video recorded and transcripts of the discussions were provided by the recruitment agency. Because the first four focus group sessions did not result in any relevant suggestion for changes, the interview materials were confirmed as final and the discussion at the end of the session was skipped in the final two focus groups.

The 15 respondents who were interviewed individually were introduced to the topic and purpose of the study by the interviewer and then conducted the ranking exercise as described above (i.e., second part of the focus group sessions). The interviews were conducted by SW and JE.

Ethics

Respondents were given an information sheet describing the aim of the study, the task they were about to perform, the intended use of the data they would provide and how their anonymity was guaranteed. They were informed that their data would only be used if they agreed to participate in the study by signing the informed consent form at the end of the focus group session or interview. They were told they were allowed to stop at any point during the session or interview, in which case any data collected up to that point would be destroyed.

In the focus group sessions, respondents were informed about the video recording of the group discussions and all agreed to being recorded for the purpose of this study.

Data analysis

The ranking data collected from the 46 respondents was subject to by-person factor analysis using a dedicated software tool: PQMethod [41]. Preliminary analysis indicated that the data supported five factors, applying the following two criteria: (i) Eigenvalue > 1 and (ii) at least two defining sorts, i.e. respondents statistically significantly associated with a factor ($p<.05$) (henceforth called 'exemplars'). Based on inspection of the correlations between factors and attempts to interpret factors from different solutions, a three factor solution was chosen as the most interpretable and coherent reduction of the data.

An idealized ranking of the statements was generated for each factor by: (i) computing the weighted mean score for each statement on that factor (i.e., the score of the statement in the ranking of exemplars for that factor multiplied by the correlation coefficient of the participant with the factor); (ii) standardizing these scores with mean 0 and standard deviation 1, to make statistical comparison possible between factors with different numbers

of associated participants; and (iii) ranking the statements from highest to lowest standardized score on the factor. This idealized ranking represents how a respondent with a 100% correlation with that factor would have ranked the 48 statements, and provides the statistical basis for interpretation and description of each factor. This is complemented with qualitative materials from the interviews of exemplars for that factor.

Results

Table 1 presents the characteristics of the 46 participants and Table 2 presents their factor loadings. Highlighted in Table 2 are the results of the 11 respondents who had personal experience with cancer. Table 3 presents the composite sorts of the statements for the three factors. Correlations between the factor scores ranged between 0.12 and 0.59 (ρ=0.30 for 1 vs. 2; ρ=0.12 for 1 vs. 3; ρ=0.59 for 2 vs. 3). In what follows, all three shared viewpoints are described. Verbatim quotes from exemplars for each factor are used to illustrate the accounts described and noted in "" with respondent id numbers. The positioning of statements is given in parenthesis with the statement number indicated by # and the positioning on the grid, for the factor in question, following the statement number. An * beside the position on the grid indicates a statistically significantly different position ($p<.01$) for that statement in relation to the factor in question, relative to the other two factors.

<u>Viewpoint 1</u>

People holding this view consider the access to healthcare a basic human right: "Everyone has the right to the same level of care regardless of age or how long you can benefit from treatment" (id 3). All patients should be treated equally, because "Everyone is equal, so also in healthcare" (id 37) and "Every human being has the right to care, regardless of age,

ethnicity, income etc" (id 18). Patient characteristics other than their health should play no role in prioritizing care (#18, +3), because to do so would be discriminating (id 3; id 18). In this viewpoint, 'access to care should be based on need for care, not on other circumstances' (#1, +4*). This need for care is an individual matter (id 3); every person is unique (id 11); and what constitutes "the right care" will be different for everyone (id 23). In line with this, people holding this viewpoint, more than those in the other viewpoints, believe that patients should be supported in their choices (#16, +1*; #46, +1*).

Distinctive for viewpoint 1 is the placement of almost all statements with an explicit reference to giving priority to some people over others on the left side of the grid. This holds for prioritization based on characteristics of the patient (#48, -4*; #34, -3*; #26, -4), characteristics of the illness (#28, -2; #27, -3*; #24, -2*), health effects of treatment (#11, -2; #31, -2*) and broader effects of treatment (#21, -3; #20, -3). Patients with terminal illnesses are no exception in this respect (#28, -2), but people holding this viewpoint also believe that 'if ways of helping patients exist, it is morally wrong to deny them the treatment' (#10, +3*) and 'if it is possible to save a life, every effort should be made to do so' (#8, +3*).

The placement of statements on cost-effectiveness suggest that people holding viewpoint 1 are not necessarily against providing treatments that have high costs in relation to their health benefits (#44, -2*; #6, +2*). In addition, distinguishing for this viewpoint is that there is no strong opinion about taking into account cost-effectiveness for end-of-life treatment (#35, 0*; 15, 0*), while people holding viewpoints 2 and 3 are in favour of doing so. Furthermore, in comparison with viewpoints 2 and 3, people holding viewpoint 1 are significantly more in agreement with respecting a patient's choice for treatment, even when the costs are high in relation to the health benefits (#46, +1*). A reason for this may be that they strongly agree with the statement that 'you can't put a price on life (#47, +4*). One

exemplar states: “We should not think in terms of money when it concerns health, human beings and human rights” (id 23).

We call this viewpoint *‘Equal right to healthcare’*.

Viewpoint 2

People holding this view have a strong concern for providing the right care for patients with terminal illnesses. They stress that ‘the right care’ is not necessarily the same as providing treatment; providing guidance towards acceptance and a dignified death may sometimes be more appropriate. This is reflected in their strong support for the statement: ‘At the end of life it is more important to provide a death with dignity than treatments that will only extend life for a short period of time’ (#2, +4*).

People holding viewpoint 2 believe that unnecessary treatments should be avoided: ‘There is no use in providing treatment when the result is still a very poor state of health’ (#40, +3). The results of treatments for terminally ill patients should be assessed in terms of quality of life (#39, +4*; #14, -4). One exemplar for this viewpoint states that treatment should only be considered “when the quality of life justifies treatment” (id 30) and another states: “Focus strictly on quality of life in the terminal phase. So no unnecessary treatments… Unnecessary treatments are life-extending treatments that decrease quality of life or at least do not increase it. Endless chemotherapy sessions instead of a nice trip to the Bahamas” (id 29).

An important aspect in viewpoint 2 is patients’ acceptance of an approaching death (#22, +3*). One exemplar states: “In the end, healthcare cannot overcome death. We should not give ourselves the impression that it can” (id 28). In this context, one exemplar emphasizes the importance of a timely start of dialogue between doctors and their patients:

“Doctors have the responsibility to explain what quality of life means, to guide patients towards accepting their death” (id 30). Another exemplar states that ‘to treat or not to treat’ is a discussion with the patient that needs to be initiated early (id 29). In line with this, people holding viewpoint 2 believe that patients’ choices for treatment need not necessarily be supported (#16, -3; #46, -2). This is also reflected in their agreement with the statement: ‘Patients at the end of life will grasp any slightest hope but that is not a good reason for continuing to provide treatment’ (#19, +2).

People holding viewpoint 2 do not seem to place great importance on cost-efficiency as a criterion in health care decision making in general (#44, 0*), but they do acknowledge that providing treatments at the end life is not good use of money when health benefits are minimal (#15, +3; #35, +2). One exemplar states: “Money should play no role when someone can be helped”, but also “A patient might want as much treatment as possible, but it is not possible to provide treatment at all costs, when health benefits are minimal” (id 4). Another exemplar states: “Spending a lot of money on treatments that only lengthen life for a short period of time, there are better ways to spend that money” (id 43).

Most of the statements that assign priority to specific groups of patients are ranked negatively, which suggests that no priority should be assigned based on those characteristics (#30, -3; #3, -3*; #48, -2*; #9, -3; #29, -2; #20, -2; #34, -2; #43, -2). One notable exception is priority setting based on people’s own responsibility for their illness (#24, +2*). One exemplar explains: “If we have to choose between similar patients, both with lung cancer but one smokes and the other does not, then smoking may be taken into account” (id 27). Self-control issues are no reason to oppose against priority based on lifestyle (#17;-3). This respondent (id 27) holds the view that, in one way or the other, people always have some level of influence over their lifestyle choices.

People holding viewpoint 2 also emphasize the importance of prevention of disease (#13, +3). Three exemplars explicitly mention the importance of prevention (id 10, id 29, id 43), two of them in combination with lifestyle: “Prevention and lifestyle are important to work out” (id 29); “Spend more money on prevention. This starts early, with children. Own responsibility plays a role, but more in prevention than in treatments”(id 43).

We call this viewpoint ‘*Limits to healthcare’*.

Viewpoint 3

People holding this viewpoint are oriented towards the outcome of treatments. They believe that priority should be given to treatments that generate the most health and patients who benefit most from treatment (#31, +4*; #32, +3*). They agree with the statement that ‘there’s no use in providing treatments when the result is still a very poor health state’ (#40, +2). Thus, patients’ capacity to benefit from treatment is important in reimbursement decisions. As one exemplar states: “Treatments that generate hardly any health benefit should not be reimbursed” (id 32). In addition, health benefits should primarily be considered in terms of quality, and not length of life (#14, -4; #30; -3), which was also emphasized in viewpoint 2.

In viewpoint 3, assessing the effectiveness of treatments in relation to their costs seems more relevant than in viewpoints 1 and 2: ‘Treatments that are very costly in relation to their health benefits should be withheld’ (#44, +1*). This is also reflected in the attitude that people holding this viewpoint have towards treatments for terminally ill patients: ‘It is not worthwhile spending money on expensive treatments for people who are not going to live very long anymore and won’t benefit very much’ (#15, +3). Thus, for end of life treatments, both the effectiveness and efficiency are important, which is reflected in the

disagreement with the statement: 'Treating people at the end of life is important, even if it is not going to result in big health gains (#41, -3); and agreement with the statement: 'Reimbursement of life-extending treatments should be decided on the basis of their costs and health benefits' (#35, +3).

Notwithstanding the focus on cost-effectiveness, people holding viewpoint 3 agree with the statement: 'You can't put a price on life' (#47, +3*). As one exemplar explains, in this viewpoint this means: "We cannot determine *one* value for a life. It depends on many circumstances (current quality of life, and age in my opinion)" and "Balancing costs and benefits is important, but priority setting should not depend on it 100%. Other considerations could justify more expensive treatments being provided to specific patient groups" (id 2). One of these circumstances is the health of children: 'Children's health should be given priority over adults' health' (#3, +4*). Another one is lifestyle: 'People who live a healthy life should be prioritized over people with an unhealthy lifestyle' (#27, +2). One exemplar of this viewpoint explains that lifestyle may be taken into account because "People are to a large extent responsible for their own health" (id 38). People holding this viewpoint disagree with the statement that lifestyle should not be taken into account because people do not always have control over their way of living (#17, -3). In line with this, one exemplar gives priority to the health of children because they cannot be taken accountable for their lifestyle: "Children do not have the responsibility to live a healthy life (while the parents do). They should therefore be given priority over adults" (id 20).

We call this viewpoint *'Effective and efficient healthcare'*.

Consensus between the viewpoints

There was consensus between all three viewpoints that the ultimate aim of the health system is getting the greatest health benefit overall for the population (#36; 2, 2, 2).

In addition, there was consensus that certain criteria should not be used in priority setting. First, prior health consumption should play no role, which is reflected in disagreement with the statements: 'People who have received a lot of health care in the past should take second place to people who have not received much health care yet' (#26; -4, -4, -3); and 'People whose treatment has been unsuccessful should be given priority for further treatment over other people' (#9; -1, -2, -2). Secondly, income and contribution to the system should play no role either. There is consensus that no priority should be given to patients who provide for the family (#20; -3, -3 -2). In addition, there is shared disagreement with the statements: 'People should be allowed to buy themselves priority treatment if it doesn't affect the treatment of others' (#23; -2, -2, -2); and 'Poorer people should be given priority because they don't have the same opportunities in life' (#29; -2, -2, -4). This is motivated by the belief that socio-economic background should not affect people's access to health care ("I believe that wealth should have nothing to do with health" (id 12, viewpoint 1)) and that buying priority treatment is unfair, because it differentiates people in their access to care based on ability to pay: "If people are allowed to buy themselves priority care, the rich have more opportunities for care, which is unfair in my opinion" (id 18, viewpoint 1); "It can never be the case that someone who has more money to spend gets priority in treatment" (id 4, viewpoint 2).

Discussion

This study aimed to explore the views of the public in the Netherlands on a range of equity and efficiency considerations that have been argued to be relevant for health care decision-making, and whether these views express support for making a special case for treatment of people with a terminal illness. This work builds on three previous Q studies eliciting societal views in this area. The current study differs from two of the related studies [12, 15] by its particular interest in the relative value of costly end of life treatments, and from the third related study [1] by exploring end-of-life considerations within a broader context of societal preferences and by including a sample of people with experience of cancer. Furthermore, the results of the current study give insight into the heterogeneity in views in Dutch society and provide a broader understanding of the ongoing public debate on priority setting in health care in the Netherlands.

This study revealed three distinct views. Our first viewpoint, called 'Equal right to healthcare', is an egalitarian view in terms of emphasizing the importance of equality in opportunities and hence access to healthcare. It denies giving priority in any circumstance, because assigning priority to some patients at the cost of others conflicts with every person's basic and equal right to healthcare. End of life situations are no exception, which translates in two directions. First, people with a terminal illness have the same right to healthcare as anyone else has, which means that they are entitled to treatment, even if this is expensive. On the other hand, no special case is made for anyone, including patients with a terminal illness. This implies that people associated with viewpoint 1 do not put higher social value on life-extending treatments for terminally ill patients. They are likely to disagree with policies that put priority on specific groups of patients and policies that restrict

patient's access to the available care. Our second viewpoint, called 'Limits to healthcare', has a strong focus on setting limits on treatment for people with a terminal illness. People holding this viewpoint make a special case for these patients in the sense that they emphasize that the care that terminal patients receive should at all times respect the patients' quality of life and dignity. People holding this viewpoint would be likely to oppose provision of invasive treatments that may give only small life extensions at the cost of a dignified end of life. They would support policies aimed at improving patient awareness with respect to end of life decision-making on the one hand and prevention and lifestyle on the other hand. In addition, they may agree with policies that limit spending on costly end of life treatments when health benefits do not outweigh costs. Our third viewpoint, called 'Effective and efficient healthcare', is oriented towards the costs and effects of treatments. In addition, people holding this viewpoint have no moral objection to priority setting, which is in sharp contrast with people holding viewpoint 1. Compared to viewpoint 2, which is primarily oriented towards the costs and effects of treatments in end of life cases, viewpoint 3 makes a stronger case for cost-effectiveness as a criterion in decision-making in general. However, they also acknowledge that other circumstances, such as lifestyle and whether a child or an adult is treated, may affect the social value placed on health gains. People holding viewpoint 3 are most likely (as compared to people holding the other viewpoints) to agree with policies that prioritize treatments based on cost-effectiveness.

Overall, we found little support in the three views for the idea that health gains in terminally ill patients are more valuable than those in other patients. The statement stating that people with terminal conditions should be treated with priority over people with non-terminal conditions (#28) was ranked from -2 in viewpoint 1 to 0 in viewpoint 3, suggesting that people's opinion about this aspect is fairly neutral. In addition, people holding

viewpoints 2 and 3 favoured incorporating efficiency arguments in decisions regarding the reimbursement of expensive life-extending treatments, which implies that they do not value these health gains higher than others. People holding viewpoint 1 do not wish to restrict access to care, and consequently also not to costly treatments, including those for terminally ill patients. However, they are unwilling to differentiate patients on any grounds, and therefore not more willing to pay for expensive treatments for terminally ill patients than for other groups of patients.

Our study included 11 respondents with personal experience with cancer. An interesting question therefore is whether this group of people differed in their views from the other respondents. The factor loadings of these 11 respondents (see Table 2) reveal that seven of them associated with viewpoint 1, two with viewpoint 2, none with viewpoint 3, and two did not associate significantly with any viewpoint. The qualitative data of our respondents (i.e. group discussions and interview materials) revealed that similar reasoning applied for choices made by exemplars throughout the sample, regardless of their personal experience with cancer, which suggests that respondents with and without experience with cancer generally did not substantially differ in their views on the topic. However, a remarkable finding from the qualitative data was that this group of cancer patients and survivors strongly emphasized the importance –and sometimes lack- of trust, dialogue and communication between medical specialists and patients. Just like exemplars for viewpoint 2, they stressed that patient involvement in treatment decisions is essential and identified a general tendency among medical specialists to focus on continuing treatment, while they (or fellow patients they talked about) did not always consider that to be in their own interest.

In this study, we built on three related Q-methodology studies [1, 12, 15], which allows for a comparison across studies. Equality in healthcare rights seems to be a central issue in

health care priority setting. In line with our first viewpoint, both the EuroVaQ [12] and the SVQ [15] studies find viewpoints that stress the relevance of a basic right to healthcare. Entitlement to healthcare, the importance of access over outcome, and opposition to priority setting based on personal characteristics are central to these accounts.

A recurrent issue in all three abovementioned studies as well as the current one is the relevance of efficient and effective health care, which is reflected in our third viewpoint. Statements expressing the relevance of maximizing health benefits for the overall population, evaluating health benefits in relation to their costs and focusing on treatments that yield the largest health benefits are clustered in one viewpoint in all these studies. In addition, people holding such a viewpoint in general do not oppose priority setting (on moral grounds), but the issues that may be taken into account in such choices, for example patients' age, differ across studies.

Our second viewpoint that focused on end-of-life treatments and a concern for efficiency and not extending life just for the sake of it seems similar to one of the viewpoints in the MRC EoL study [1]. Nonetheless, people holding these viewpoints appear to differ in their perception of short life extension at the end of life. In our study, short life extensions were primarily associated with decreased quality of life and increased suffering from invasive treatments, at the cost of a dignified end of life and therefore considered as undesirable. In McHugh et al. [1], short life extensions were primarily associated with the additional time provided to patients and their families to say their goodbyes and put their affairs in order, thus contributing to a dignified end of life. This difference may be partly explained by the selection of statements in the current study. The MRC EoL study included specific statements about preparation for death, as for example: "It is important to give a dying person and their family time to prepare for their death, put their affairs in order, make

peace and say goodbyes" (MRC EoL statement #11) and "It's important to provide life-extending treatments to give a dying person time to reach a significant milestone, like a family event or a personal achievement" (MRC EoL statement #47). The current study addressed this issue at a far more general level by statement #30 ("Priority should be given to life-extending treatments to patients who have only recently found out that they are going to die soon."). The broader context of our study required us to make a different selection of statements, and we judged this general statement to be more relevant in the context of health care priority setting. In addition, this difference in perception of short life extensions may also be explained by the socio-political context of the studies (i.e. the Netherlands vs. UK).

Our study, as well as the three abovementioned Q-methodology studies, reveal viewpoints that seem incommensurable. On the one hand, we find people who morally object to priority setting and restricting available care on the basis of universal rights to healthcare, thereby apparently denying the need to face issues of scarcity. On the other hand, we find people who accept priority setting as a necessary means to make decisions about allocation of a fixed health care budget, recognizing scarcity in health care resources, but differing in whether and how to weight the outcomes of healthcare. The tension between these viewpoints reflects an ethical debate between consequentialist reasoning, found in efficiency related viewpoints, and deontological reasoning, found in egalitarian viewpoints. Consequentialist ethics puts focus on the consequences of actions. It states that right acts are those that produce the best overall outcome, as judged from an impersonal standpoint that gives equal weight to the interests of everyone. Deontological (or agent-relative) ethics prohibits the performance of acts that violate our moral code of conduct, i.e.

acts that are in violation of the duties and rights that we have, regardless of their outcomes [42].

Consequentialist and deontological ethics are difficult to reconcile. Indeed, people holding viewpoint 1 in our study may agree fully to the 'more health is better' principle, but believe that this does not justify a violation of people's basic rights and entitlements. Similarly, people holding viewpoint 3 may fully agree with the idea of universal rights and entitlements, but that does not justify unlimited spending on healthcare and on people whose benefit from treatment is limited. The challenge for policy makers is to find compromises that do justice to both "sides", or to explain their choices to those people in society with opposing views.

Scarcity was a central point of departure for this study, but people whose views align with viewpoint 1 essentially seem to deny scarcity from the position that care is a basic right. The current study does not provide further insight into how people with this viewpoint reconcile a desire for unlimited access to healthcare with the reality of a limited healthcare budget, this would be an interesting topic for further study. Are these people willing to spend a larger proportion of public or personal budgets on healthcare, how much would that be, and at the cost of what else?

Limitations

It is important to highlight some limitations of our study. First of all, Q methodology may reveal the viewpoints society in the Netherlands holds, but it does not provide insight into the prevalence of these views among the public. Our results therefore do not provide clear policy guidance in this respect; for this purpose, additional research is needed to determine how common the viewpoints are. There are several techniques to examine factor

membership in a representative sample of the public [15, 43, 44]. In such research, it may also be interesting to explore the relationship of factor membership with socio-demographic characteristics of respondents, their wider socio-political orientation, and their opinion with respect to specific choices in the context of health care priority setting, as faced by decision makers.

Secondly, we followed a careful procedure to obtain our statement set, but to arrive at our short list of 48 statements from our long list of 129 statements, choices were made. Our aim was to arrive at a comprehensive, manageable statement set reflecting the existing issues in society but given the broad scope of this topic, we acknowledge that different choices could have been made both in the detail of each individual statement and in the framework initially used to categorise statements and ensure that all domains of relevance were included. In addition, we aimed to develop a statement set that was balanced in presenting each aspect at a comparable level of abstraction and detail, to minimize the influence of our selection of statements on the possibility for respondents to reveal their viewpoint. In the pilot study participants were explicitly asked whether they missed any important topics in the statement set, and in the main study participants also had the opportunity to comment on the research materials. Based on this, we have no indication that we missed important domains or aspects in the development of the statement set. We believe that a different statement set representing the same domains and aspects (as shown in the Annex) is unlikely to expose substantially different underlying positions.

Thirdly, while we recruited respondents using a carefully designed sampling frame, it is difficult to be absolutely certain that data saturation was achieved (or is achievable) and that all different viewpoints in society are covered in this study. Additional research, alluded to above, investigating the prevalence of the three viewpoints in society identified here would

be helpful. If such a study would expose sizeable groups of respondents that did not identify their views in any of the three viewpoints, this would indicate that other perspectives exist that we have failed to identify in this analysis.

Conclusion

This study has generated new understanding of the viewpoints in Dutch society about priority setting in health care in general, and in end-of-life situations in particular. Compared to the existing studies, this is the first to assess end-of-life considerations within a broader context of societal preferences. Three viewpoints, called '*Equal right to healthcare*', '*Limits to healthcare*', and '*Effective and efficient healthcare '* were identified, but in none of these viewpoints we found direct support for making a special case for life-extending treatments for people with a terminal illness. This suggests that there may be little public support for the policy assumption that health gains in terminally ill patients are considered to be more valuable than those in other patients.

Tables and Figures

References

1. McHugh N, Baker RM, Mason H, Williamson L, van Exel J, Deogaonkar R, Collins M, Donaldson C: Extending life for people with a terminal illness: a moral right and an expensive death? Exploring societal perspectives. BMC medical ethics 2015, 16(1):14.

2. Banta D: The development of health technology assessment. Health Policy 2003, 63(2):121-132.

3. Jonsson E: Development of health technology assessment in Europe. Int J Technol Assess Health Care 2002, 18(02):171-183.

4. Brouwer WB, Van Exel N, Baltussen RM, Rutten FF: A dollar is a dollar is a dollar—or is it? Value in Health 2006, 9(5):341-347.

5. Weinstein MC, Torrance G, McGuire A: QALYs: the basics. Value in health 2009, 12(s1):S5-S9.

6. Devlin N, Appleby J, Parkin D: Patients' views of explicit rationing: what are the implications for health service decision-making? J Health Serv Res Policy 2003, 8(3):183-186.

7. Dolan P, Shaw R, Tsuchiya A, Williams A: QALY maximisation and people's preferences: a methodological review of the literature. Health Econ 2005, 14(2):197-208.

8. Nord E, Johansen R: Concerns for severity in priority setting in health care: A review of trade-off data in preference studies and implications for societal willingness to pay for a QALY. Health Policy 2014, 116(2):281-288.

9. Schwappach DL: Resource allocation, social values and the QALY: a review of the debate and empirical evidence. Health Expectations 2002, 5(3):210-222.

10. Shah KK: Severity of illness and priority setting in healthcare: a review of the literature. Health Policy 2009, 93(2):77-84.

11. Tsuchiya A, Dolan P, Shaw R: Measuring people's preferences regarding ageism in health: some methodological issues and some fresh evidence. Soc Sci Med 2003, 57(4):687-696.

12. van Exel J, Baker R, Mason H, Donaldson C, Brouwer W, Team E: Public views on principles for health care priority setting: Findings of a European cross-country study using Q methodology. Soc Sci Med 2015, 126:128-137.

13. Whitty JA, Lancsar E, Rixon K, Golenko X, Ratcliffe J: A Systematic Review of Stated Preference Studies Reporting Public Preferences for Healthcare Priority Setting. The Patient-Patient-Centered Outcomes Research 2014, :1-22.

14. Van de Wetering E, Stolk E, Van Exel N, Brouwer W: Balancing equity and efficiency in the Dutch basic benefits package using the principle of proportional shortfall. The European Journal of Health Economics 2013, 14(1):107-115.

15. Baker R, Wildman J, Mason H, Donaldson C: Q-ing for health - A new approach to eliciting the public's views on health care resource allocation. Health Econ 2014, 23(3):283-297.

16. van de Wetering L, van Exel J, Bobinac A, Brouwer WB: Valuing QALYs in Relation to Equity Considerations Using a Discrete Choice Experiment. Pharmacoeconomics 2015, 33:1289-1300.

17. Collins M, Latimer N: NICE's end of life decision making scheme: impact on population health. BMJ: British Medical Journal 2013, 346.

18. Cookson R: Can the NICE "End-of-Life Premium" Be Given a Coherent Ethical Justification? J Health Polit Policy Law 2013, 38(6):1129-1148.

19. Sorenson C: Valuing end-of-life care in the United States: the case of new cancer drugs. Health Economics, Policy and Law 2012, 7(04):411-430.

20. Shah KK, Cookson R, Culyer AJ, Littlejohns P: NICE's social value judgements about equity in health and health care. Health Economics, Policy and Law 2013, 8(02):145-165.

21. NICE: Appraising life-extending, end of life treatments. 2009, :.

22. Shah KK, Tsuchiya A, Wailoo AJ: Valuing health at the end of life: an empirical study of public preferences. The European Journal of Health Economics 2014, 15(4):389-399.

23. Pennington M, Baker R, Brouwer W, Mason H, Hansen DG, Robinson A, Donaldson C: Comparing WTP values of different types of QALY gain elicited from the general public. Health Econ 2015, 24(3):280-293.

24. Brazier J, Rowen D, Mukuria C, Whyte S, Rise Hole A, Tsuchiya A, Schackley P: Eliciting societal preferences for burden of illness, therapeutic improvement and end of life for value based pricing: a report of the main survey. 2013, :.

25. Pinto-Prades J, Sánchez-Martínez F, Corbacho B, Baker R: Valuing qalys at the end of Life. Soc Sci Med 2014, 113:5-14.

26. Shah KK, Tsuchiya A, Wailoo AJ: Valuing health at the end of life: A stated preference discrete choice experiment. Soc Sci Med 2015, 124:48-56.

27. Olsen JA: Priority preferences: "End of life" does not matter, but total life does. Value in Health 2013, 16(6):1063-1066.

28. Linley WG, Hughes DA: Societal views on NICE, cancer drugs fund and value-based pricing criteria for prioritising medicines: A cross-sectional survey of 4118 adults in Great Britain. Health Econ 2013, 22(8):948-964.

29. CVZ: Richtlijnen voor farmaco-economisch onderzoek, geactualiseerde versie. 2006, :.

30. Franken M, le Polain M, Cleemput I, Koopmanschap M: Similarities and differences between five European drug reimbursement systems. Int J Technol Assess Health Care 2012, 28(04):349-357.

31. RVZ: Zinnige en duurzame zorg. 2006, :.

32. CVZ: Pakketbeheer in de Praktijk 2. 2009, :.

33. Stolk EA, van Donselaar G, Brouwer WB, Busschbach JJ: Reconciliation of economic concerns and health policy. Pharmacoeconomics 2004, 22(17):1097-1107.

34. Busschbach JJ, Delwel GO: Het pakketprincipe kosteneffectiviteit achtergrondstudie ten behoeve van de 'appraisal' fase in pakketbeheer: Diemen: Health Care Insurance Board; 2010.

35. Watts S, Stenner P: Doing Q methodological research: Theory, Method & Interpretation: London: Sage; 2012.

36. McKeown BF, Thomas DB: Q methodology (Quantitative applications in the social sciences series, vol. 66): 2nd ed. Thousand Oaks, CA: Sage; 2013.

37. De Graaf G, Van Exel J: Using Q methodology in administrative ethics. Public Integrity 2008, 11(1):63-78.

38. Kline P: An Easy Guide to Factor Analysis: New York: Routledge; 1994.

39. Bobinac A, van Exel N, Rutten FF, Brouwer WB, Van Exel N: Inquiry into the Relationship between Equity Weights and the Value of the QALY. Value in Health 2012, 15(8):1119-1126.

40. Van Dijk HM, Cramm JM, Van Exel J, Nieboer AP: The ideal neighbourhood for ageing in place as perceived by frail and non-frail community-dwelling older people. Ageing and Society 2015, 38(8):1771-1795.

41. Schmolck P, Atkinson J: PQ Method software and manual 2.11. 2002, :.

42. Scheffler S: Agent-centred restrictions, rationality, and the virtues. In Consequentialism and its Critics. Edited by Scheffler S. Oxford University Press; 1988:243-260.

43. Baker R, van Exel J, Mason H, Stricklin M: Connecting Q and surveys: three methods to explore factor membership in large samples. Operant Subjectivity 2010, 34(1):38-58.

44. van Exel J, de Graaf G, Brouwer W: Give me a break!: Informal caregiver attitudes towards respite care. Health Policy 2008, 88(1):73-87.

Table 1 Sample characteristics (n=46)

Characteristic		N (%)
Age	18-35	10
	35-55	24
	55+	12
Sex	Female	26
	Male	20
Education level	Low	15
	Middle	11
	High	20
Children	No	35
	Yes	11
Religious*	No	16
	Yes	9
	Unknown	21
Personal experience with cancer	No	35
	Yes	11

* Respondents were asked to which religious community or ideological grouping they considered themselves; those who indicated 'none' were categorized as not religious, all others were categorized as religious. The question about religiosity was not asked in the first four focus group sessions and therefore this information is unknown for these 21 respondents.

Table 2 Factor loadings

Respondent	Factor 1	Factor 2	Factor 3
Personal experience with cancer [a]			
005	0.43	0.63*	0.17
006	0.05	0.01	0.17
008	0.68*	0.31	0.08
011	0.75*	0.02	0.18
014	0.42*	-0.03	0.11
016	0.71*	0.06	0.16
018	0.77*	0.04	-0.01
019	-0.06	0.49*	0.42
021	0.76*	-0.07	0.12
022	0.74*	0.01	0.25
045	-0.13	0.14	0.00
No personal experience with cancer			
001	-0.30	0.47*	0.32
002	-0.03	0.15	0.60*
003	0.75*	0.18	0.01
004	0.29	0.53*	0.31
007	0.44*	0.26	0.25
009	0.52*	0.23	0.11
010	0.36	0.52*	0.04
012	0.76*	0.15	0.14
013	0.48*	0.08	0.30
015	0.43*	0.37	0.15
017	0.62	0.30	-0.06
020	0.12	0.02	0.49*
023	0.54*	0.36	-0.07
024	-0.20	0.13	0.48*
025	0.48	0.50*	-0.03
026	0.08	0.33	0.62*
027	-0.27	0.69*	0.48
028	0.15	0.70*	0.12

Respondent	Factor 1	Factor 2	Factor 3
029	0.01	0.55*	0.38
030	0.25	0.56*	0.33
031	0.83*	0.09	0.05
032	0.14	0.41	0.49*
033	0.63*	0.14	-0.20
034	0.71*	-0.30	0.03
035	0.74*	0.18	-0.19
036	0.71*	0.07	0.13
037	0.83*	-0.15	-0.05
038	0.01	0.09	0.29*
039	0.07	0.34*	0.05
040	0.78*	0.31	-0.20
041	0.61*	0.14	0.26
042	0.35*	0.22	-0.20
043	0.03	0.59*	0.39
044	0.20	0.14	0.27
046	0.30	0.26	0.38

Notes:

[a] *participants who identified themselves as cancer patient or survivor during recruitement.* denotes defining Q sort for factor, which means that Q sort loads statistically significantly (p<.05) on factor (i.e. correlation coefficient is larger than* $\frac{1.96}{\sqrt{48}}$ *= 0.283) and is not confounded between factors (i.e. square of correlation coefficient on factor is larger than sum of squares of correlation coefficients on other two factors).*

Table 3 Factor scores per statement

Statement		F1	F2	F3
1	Access to health care should be based on need for care, not on other circumstances.	+4*	+2	+2
2	At the end of life it is more important to provide a death with dignity than treatments that will only extend life for a short period of time.	+2	+4*	+2
3	Children's health should be given priority over adults' health.	-1*	-3*	+4*
4	Everyone has a right to healthcare, but this does not extend beyond a certain basic level.	-1	-1	-1
5	If a special case can be made for expensive treatments for certain patient groups, an equal case could be made for other patient groups.	+1	+1	-1*
6	If a treatment is costly in relation to its health benefits, but the only treatment available, it should still be provided.	+2*	+1*	0*
7	If either 10 people could each get a large health benefit or 100 people each a small one, it is better to treat the 100 people.	0	0	-2*
8	If it is possible to save a life, every effort should be made to do so.	+3*	0	-2
9	People whose treatment has been unsuccessful should be given priority for further treatment over other people.	-1	-2	-2
10	If there is a way of helping patients, it is morally wrong to deny them this treatment.	+3*	+1	+1
11	If two groups of patients can benefit from a treatment equally, priority should be given to the patients whose quality of life before treatment is lowest.	-2	0	+1*
12	Individual responsibility should not be considered because it is never straightforward what the actual cause of illness is.	+2*	0*	-1*
13	It is more important to prevent ill health than it is to cure ill health once it occurs.	+2	+3	+2
14	It is more important to provide treatments that prolong life of people who are terminally ill than treatments that improve their quality of life.	-1*	-4	-4

	Statement	F1	F2	F3
15	It’s not worthwhile spending money on expensive treatments for people who are not going to live very long anymore and won’t benefit very much.	0*	+3	+3
16	It's important to respect the wishes of patients who feel they should take every opportunity to extend their life.	+1*	-3	-1
17	Lifestyle should not be taken into account because people don’t always have control over their way of living.	+3*	-3	-3
18	Patient characteristics other than their health should play no role in prioritising care.	+3*	0	-1
19	Patients at the end of life will grasp any slightest hope but that is not a good reason for continuing to provide treatment.	0*	+2	+1
20	Patients who provide for others should be prioritised.	-3	-2	-2
21	Patients with a family should be prioritised because their treatments will benefit others as well as the patient themselves.	-3	-1	-1
22	People should accept that if it's your time to die, it's your time.	0	+3*	0
23	People should be allowed to buy themselves priority treatment if it doesn’t affect the treatment of others negatively.	-2	-2	-2
24	People who are in some way responsible for their own illness should receive lower priority than people who are ill through no fault of their own.	-2*	+2*	0*
25	People who have paid health care premiums all their lives deserve treatment when they need it.	+2*	0	0
26	People who have received a lot of health care in the past should take second place to people who have not received much health care yet.	-4	-4	-3
27	People who live a healthy life should be prioritized over people with an unhealthy lifestyle.	-3*	+1	+2
28	People with terminal conditions should be treated with priority over people with non-terminal conditions.	-2	-1	0
29	Poorer people should be given priority because they don’t have the same opportunities in life.	-2	-2	-4*
30	Priority should be given to life-extending treatments to patients who have only recently found out that they are going to die soon.	0*	-3	-3
31	Priority should be given to patients who benefit most from treatment.	-1*	+1*	+4*

	Statement	F1	F2	F3
32	Priority should be given to those treatments that generate the most health.	+1	+1	+3*
33	Priority should be given to restoring health to a level that is sufficient for people to participate in their usual activities.	+1	+1	0
34	Priority should be given to younger people, because they may benefit from treatment for longer.	-3*	-1*	0*
35	Reimbursement of life-extending treatments should be decided on the basis of their cost and health benefits.	0*	+2	+3
36	The health system should be about getting the greatest health benefit overall for the population.	+2	+2	+2
37	The health system should be about looking after those patients in greatest need.	+1	0*	+1
38	There is no point providing treatments that will only extend life for a short time.	-1*	+2	+1
39	There is no sense in saving lives if the quality of those lives will be really bad.	0	+4*	-2
40	There's no use in providing treatment when the result is still a very poor state of health.	0*	+3	+2
41	Treating people at the end of life is important, even if it is not going to result in big health gains.	+1*	-1	-3
42	Treating terminally ill patients as more 'worthy' of receiving care undervalues the health of other patients.	0*	-1*	+1*
43	Treatment of illnesses that put a high burden on patients' families should receive priority.	-1	-1	0*
44	Treatments that are very costly in relation to their health benefits should be withheld.	-2*	0*	+1*
45	Treatments that provide a short life extension are only prolonging the pain for the patient's family and friends.	0	0	0
46	We should support patients' choice for treatment, even if it is very costly in relation to its health benefits.	+1*	-2	-1
47	You can't put a price on life.	+4*	0*	+3*
48	Younger people should be given priority over older people, because they haven't had their fair share of health yet.	-4*	-2*	0*

*Note: * p<.01*

Annex Final set of 48 statements according to domains and characteristics from empirical framework

Domain	Characteristic	Nr	Statements
A. Characteristics of the patient	1. Age(ism) / fair innings	48	Younger people should be given priority over older people, because they haven't had their fair share of health yet.
		34	Priority should be given to younger people, because they may benefit from treatment for longer.
		3	Children's health should be given priority over adults' health.
	2. Prior health consumption / previous health profile	9	People whose treatment has been unsuccessful should be given priority for further treatment over other people.
		26	People who have received a lot of health care in the past should take second place to people who have not received much health care yet.
B. Characteristics of the illness	3. Severity	28	People with terminal conditions should be treated with priority over people with non-terminal conditions.
	4. Rule of rescue	8	If it is possible to save a life, every effort should be made to do so.
	5. Probable cause / culpability	27	People who live a healthy life should be prioritized over people with an unhealthy lifestyle.
		24	People who are in some way responsible for their own illness should receive lower priority than people who are ill through no fault of their own.
		17	Lifestyle should not be taken into account because people don't always have control over their way of living.
		12	Individual responsibility should not be considered because it is never straightforward what the actual cause of illness is.

Domain	Characteristic	Nr	Statements
C. Characteristics of the treatment	6. Availability	6	If a treatment is costly in relation to its health benefits, but the only treatment available, it should still be provided.
	7. Efficiency	44	Treatments that are very costly in relation to their health benefits should be withheld.
		35	Reimbursement of life-extending treatments should be decided on the basis of their cost and health benefits.
		15	It's not worthwhile spending money on expensive treatments for people who are not going to live very long anymore and won't benefit very much.
D. Health effects of treatment	8. Size of the effect	32	Priority should be given to those treatments that generate the most health.
		36	The health system should be about getting the greatest health benefit overall for the population.
		37	The health system should be about looking after those patients in greatest need.
		41	Treating people at the end of life is important, even if it is not going to result in big health gains.
	9. Length vs. quality of life	39	There is no sense in saving lives if the quality of those lives will be really bad.
		14	It is more important to provide treatments that prolong life of people who are terminally ill than treatments that improve their quality of life.
	10. Distribution of fixed health gains / threshold effect	7	If either 10 people could each get a large health benefit or 100 people each a small one, it is better to treat the 100 people.
	11. Start-point before / end-point after treatment	11	If two groups of patients can benefit from a treatment equally, priority should be given to the patients whose quality of life before treatment is lowest.
		33	Priority should be given to restoring health to a level that is sufficient for people to participate in their usual activities.

Domain	Characteristic	Nr	Statements
		40	There's no use in providing treatment when the result is still a very poor state of health.
	12. Direction of the effect: health gain / loss avoidance	13	It is more important to prevent ill health than it is to cure ill health once it occurs.
	13. Capacity to benefit	31	Priority should be given to patients who benefit most from treatment.
		38	There is no point providing treatments that will only extend life for a short time.
E. Broader effects of treatment	14. Being dependent / caregiving effect	43	Treatment of illnesses that put a high burden on patients' families should receive priority.
	15. Having dependents / family effect / productivity	20	Patients who provide for others should be prioritised.
		21	Patients with a family should be prioritised because their treatments will benefit others as well as the patient themselves.
		45	Treatments that provide a short life extension are only prolonging the pain for the patient's family and friends.
	16. Dignified end of life	30	Priority should be given to life-extending treatments to patients who have only recently found out that they are going to die soon.
		2	At the end of life it is more important to provide a death with dignity than treatments that will only extend life for a short period of time.
F. Moral principles	17. Patient choice	46	We should support patients' choice for treatment, even if it is very costly in relation to its health benefits.
		16	It's important to respect the wishes of patients who feel they should take every opportunity to extend their life.
		19	Patients at the end of life will grasp any slightest hope but that is not a good reason for continuing to provide treatment.

Domain	Characteristic	Nr	Statements
	18. Values	22	People should accept that if it's your time to die, it's your time.
		47	You can't put a price on life.
		10	If there is a way of helping patients, it is morally wrong to deny them this treatment.
		4	Everyone has a right to healthcare, but this does not extend beyond a certain basic level.
	19. Income / contribution	23	People should be allowed to buy themselves priority treatment if it doesn't affect the treatment of others negatively.
		29	Poorer people should be given priority because they don't have the same opportunities in life.
		25	People who have paid health care premiums all their lives deserve treatment when they need it.
	20. Equality	1	Access to health care should be based on need for care, not on other circumstances.
		18	Patient characteristics other than their health should play no role in prioritising care.
		5	If a special case can be made for expensive treatments for certain patient groups, an equal case could be made for other patient groups.
		42	Treating terminally ill patients as more 'worthy' of receiving care undervalues the health of other patients.

Notes: Five characteristics from the theoretical structure of the EuroVaQ project were disregarded: rarity, side-effects / invasiveness, certainty of the effect occurring, prospective health / prognostic difference, and productivity / work.